

Social supports in inclusive settings: An essential component to community living

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Inclusion has increased the participation rates of individuals with disabilities in school, employment and recreation activities. Proper supports are needed in these environments to encourage adequate self-esteem and successful social interactions. Without positive social interactions, individuals may experience loneliness and isolation that could negatively affect emotional and physical health. This project provides insight into the inclusive experiences of persons with developmental disabilities through in-depth interviews. The data showed that social supports (i.e., family, peers, and church) are an essential component of successful community living. A rural advantage was evident, in that the community as a whole acted as an informal support system.

Introduction

Currently, there is a drive to promote the inclusion of all individuals in school, work, and leisure activities. People with developmental disabilities, once relegated to institutional facilities, tend now to live in their home communities (Anderson, Lakin, Mangan, & Prouty, 1998). In a similar vein, individuals with developmental disabilities are increasingly more visible within Canadian communities, more often taking part in activities with their non-disabled peers. The inclusion of individuals with disabilities is carried out with the intent of increasing social interactions and preparing them for active roles in their community; however, without the proper supports in place to ensure “authentic inclusion” (Andrews & Lupart, 2000; Ferguson, 1995), the opposite outcome may occur.

Inclusion is not simply an issue of placement. General education teachers and community leaders often assume little ownership for an individual’s

needs and operate their classrooms and workplaces as if all individuals function in the same manner (Wood 1998). Ideally, in an educational setting, inclusion is:

a unified system of public education that incorporates all children and youth as active, fully participating members of the school community; that views diversity as the norm; and that ensures a high-quality education for each student by providing meaningful curriculum, effective teaching, and necessary supports for each student. (Ferguson, 1995, p. 286)

For the purposes of this paper, the term *inclusion* will refer to an extension of Ferguson's definition to include individuals in all settings in the community. In other words, the term will signify a unified community that incorporates all individuals as fully participating members of the community; that ensures high quality service by providing the necessary supports to meet the specific needs of all persons over the lifespan. Without provision of essential adaptations, an individual with disabilities may become isolated (McDonald & Thomas, 2003). Specialized services and physical supports are necessary components for successful inclusion, but these alone may not be sufficient. Often, additional informal supports such as friendships and other social relationships are required.

Social relationships and interactions are critical to the emotional, social, and physical well being of individuals with disabilities. Social context affects more than just attitudes and beliefs, it also influences how and what one thinks (Bodrova & Leong, 1991). One becomes a self-regulating, contributing community member through opportunities for social interactions (Penual & Wertsch, 1995). Those with established friendships are more likely to have positive self-esteem, a sense of belonging, better communication skills, better emotional functioning, positive coping strategies, improved problem solving ability, a strong sense of self, a better grasp of life skills, and reduced behavioural outbursts (Heiman, 2000; Schleien, Heyne, Rynders, & McAvoy, 1990; Smith, 1981). Unfortunately, research has shown that persons with

disabilities tend to have fewer friends and less stable friendships than their non-disabled peers (Zetlin & Murtaugh, 1988).

According to Stainback and Stainback (1987), the opportunity to live and play with other children in the neighbourhood is a “crucial ingredient” of friendship formation. Evidence of this is available in the peer acceptance literature. For example, Turnbull, Periera, and Blue-Banning (1999) found that one child’s experiences of alienation stopped once he/she entered his/her community school. Children who are segregated for even a portion of the day tend to feel rejected (Freeman & Kasari, 1998) and are often viewed as “visitors” to the class (Giangreco, Edelman, Cloninger, & Dennis, 1993). If, however, they start school in an inclusive classroom they begin their school career as an “insider” (Hall & MacGregor, 2000).

With the contemporary trend toward inclusion, research on inclusive practice has increased considerably (Palmer et al., 1998). Although many studies have focussed on children and adolescents with developmental disabilities (Favazza, 1998, Kane, 1993, McDonnell et al., 2003), few have dealt with adults with these disorders. Furthermore, numerous studies have explored inclusion from the perspectives of parents and service providers (Buysse, Wesley, Bryant, & Gardner, 1999; Devore, & Hanley-Maxwell, 2000; Martin, 1996; Riehl, 2000; Wood 1998) but none have examined the perspectives of the individuals living with the disability. Many researchers have described the importance of representing the “voice” of children and adults with disabilities in the study of inclusion to identify what makes inclusion successful and what challenges still need to be overcome (Allan, 1999; Brown, 1999; Goode 1999; Mittler, 2000; Timmons 1999). To overcome the limitations of previous research, this study focussed on the personal social experiences of persons with developmental disabilities of all ages.

Method

Sample Description and Data Collection

This report is part of a larger study entitled “Inclusion across the Lifespan.” In striving to understand the overall inclusive experiences of individuals with disabilities, many conversations about social supports occurred during the data collection. These conversations are the basis of this research report.

The participants in this study represented six age groups, ranging from preschool (i.e., 3-6 years old) to senior citizen (i.e., 51 years and up), each comprised of 5-7 participants, from both urban and rural communities. The 36 key individuals included in the sample were interviewed twice over a 2-year period. These interviews were semi-structured and designed to allow the participants to talk freely about their perceptions and experiences of inclusion. The researcher used a list of questions as a guide (see table 1 for sample questions) and modified the questions as needed to meet the individual needs of the participants. For example, some participants’ disabilities interfered with their ability to speak spontaneously about their experiences so the interviewer would ask more direct questions about specific events. Other participants did not understand the language that the researcher was using so the researcher would simplify it to better accommodate the individuals’ receptive language needs. Parents or guardians were also interviewed to supplement the participants’ accounts. All interviews were audio-recorded using a digital recorder and transcribed verbatim for further analysis.

Table 1
Sample participant interview questions from the Inclusion Across the Lifespan Research Project

<p><u>Family</u></p> <ol style="list-style-type: none"> 1. What types of activities do you do with your family? 2. How does your family support you? <p><u>Friends</u></p> <ol style="list-style-type: none"> 3. Tell me about your friends. 4. What do you like to do with your friends 5. How do your friends support you? 6. How do you support your friends? <p><u>School/Work</u></p> <ol style="list-style-type: none"> 7. What do you like about your school/workplace? 8. What don't you like about your school/workplace? <p><u>Leisure</u></p> <ol style="list-style-type: none"> 9. What do you like to do after school/work? 10. What do you like to do on the weekends? 11. Do you exercise? If so, what do you do? 12. Do you play any sports? If so, what? 13. Are you part of the Special Olympics? <p><u>Community</u></p> <ol style="list-style-type: none"> 14. What do you like about where you live? 15. Is there anything you would change about where you live? If so, what?

Theoretical Framework

Qualitative researchers hold the view that "reality is constructed by individuals interacting in their social worlds" (Merriam, 1998, p. 6), therefore, a constructivist paradigm was deemed to be appropriate for this study. Within this paradigm, the researcher has to examine how people interpret their experiences in inclusive environments and what meaning they attribute to these experiences (Scott & Usher, 1999). Persons with developmental disabilities who experience inclusive settings are the most competent informants on this topic. They have a pivotal role in defining what the "truth" is in this type of inquiry.

This does not mean, however, that there is only one “truth” as multiple realities may exist side by side (Guba & Lincoln, 1991). The success of the inquiry in this paradigm is judged on the increased understanding of the phenomenon being studied.

Data Analysis

A thematic analysis (Kvale, 1996) was conducted on all interviews. The researchers were like miners or travellers searching for the experiences of the individuals and the meanings of these experiences. Constructing themes (i.e., ideas of unified or wholistic meanings) made the data less ambiguous and helped to construct the stories (Van Manen, 1997). First, each transcript was coded for common themes and trends using the qualitative data analysis package NUDIST (N6, 2002). Although the concept seems straightforward, Marshall (2002) states that researchers should never think of coding as a one step process as it involves multiple steps that may include revising, moving, or deleting codes throughout the process. This process became apparent in this study as the researchers coded and recoded data in the search for understanding. All transcripts were uploaded into the qualitative data analysis package where the researcher could organize each file line by line into codes and sub-codes, thus allowing common trends to emerge across experiences. Following this initial coding, codes were organized into broader themes and categories to create a picture of the social supports of individuals with developmental disabilities. Themes were often beneath the surface and “emerged from the data” (i.e., they are not always apparent until one becomes familiar with the data).

Presuppositions of the Researchers

The principle researcher entered the research settings with her own pre-understanding and subjectivities. To maintain the trustworthiness of the data collection and analysis, it is important for the researcher to acknowledge these biases so others can understand the *lens* the data was analyzed through (Merriam, 2002). The principle researcher had worked as a support person for many children and adults with disabilities. It is her belief and understanding that inclusion is an essential component to

maintaining a successful social life. It is through networking within the community that individuals learn life skills and meet persons that can assist them in reaching their goals.

In addition, the principle researcher has worked in both successful and unsuccessful inclusive settings and strongly holds the view that many settings that claim to be inclusive are in fact very exclusive in nature. It is the researcher's belief that an individual can be placed in an environment with his/her non-disabled peers and still be excluded until the proper supports are offered. These supports are individual in nature and wholly dependent on the specific needs of the individual.

Results

Family Support

When participants were asked to discuss their current living situations, family support was identified as one of the essential components to successful inclusion. Those individuals who experienced family conflict or tension reported greater challenges. A 63-year-old female gave one example of this conflict and how it had prevented her from gaining adequate familial support:

No, they're dead. They're gone up to heaven. Mom, she had a serious (fists on head)...just a minute....she had a serious attack there for a few minutes. Dad, he would come home one day drunk as all get out, he drinks just like anybody and he'd go out yonder somewhere and drinks and come back at midnight. And one day I was in the TV room watching TV – just like I do here, and Dad came storming home one day....I figured mom would come down with a nervous breakdown one of these days. So I didn't....I went home for Christmas just once...

Family support did not always have to come from the parents of the participants, and in many cases siblings took on a supportive role in the lives of the individuals with disabilities. Often times, this supportive role assisted the participants in being better included in their communities.

Siblings assisted in modelling social skills, introducing the individuals with disabilities to potential friends, and enhancing self-esteem so the individuals were willing to take greater risks. One participant described how all members of his family, including his brother, assisted him in this way:

They drive me, help me call people to make arrangements to go out, drive friends, most of all believe in me (18 year old male).

Without the support of their siblings, some of the participants would have limited opportunity for social interactions.

Friend Support

Friends also played a significant role in the lives of the individuals with developmental disabilities. As reported by the parents and family members, those participants who experienced a lack of friendships and loneliness were reported as having less successful inclusive experiences. Both friends with and without disabilities were identified as a support system for the individuals with disabilities. Many times, service providers strove to foster relationships between persons with disabilities and their non-disabled peers with little attention being focussed on fostering relationships between persons with disabilities. Some parents in this research project identified the importance of their children's friends with disabilities as they provide an *island of confidence* for their children. One parent stated:

But I also have some strong feelings around the fact that many times we've swung so far to the process of integration, and this is certainly only certain programs. I have some struggles with the [one particular post-secondary program] and some of the stuff that the [association] does. And it seems to me it is inclusion at the expense of their peers [with disabilities], of having friends that they're comfortable with, you know. And I feel like somewhere in that, I project some judgments onto parents on their journey. And I don't know—this is not universal; it is not across the board—but so many who don't

want their disabled children/adults integrated with other peers [with disabilities], it seems to me that they haven't really allowed their children to be who they are, you know (mother of 32 year old and 35 year old males).

Friendships between two individuals with disabilities tended to be more reciprocal. A sense of comfort was reported when the participants were able to spend time with their friends who also had disabilities because they shared common experiences. In addition, the participants were able to gain confidence through interactions with their peers with disabilities because they could act as the "helper" to their friends with disabilities and did not always have to be the receiver of help. One mother described her daughter's experience as a "helper" in a social group for individuals with disabilities:

But it was interesting, because for her, it put her in a position of being the helper, not the one getting help. And because there's such a range among the participants, she loves it (mother of 26 year old female).

Social Support in School/Work

In addition to friends and families, other forms of support emerged as significant themes. In conversations about work and school, the participants and their parents/guardians identified the social aspects of those settings as most important. When one of the adult participants was asked what he liked about his work place he simply stated that he liked "meeting people and having fun" (63 year old male). Another participant reported her concerns about leaving the social support of her workplace:

That I get....I like it because I get lots of friends there – meet lots of friends. But I told everybody.....and they're like....one thing about it though is that one of my people is really going to miss me though and I know it right now and I know who it's going to be the most who miss me – it's going to be basically all my best friends here (30 year old female).

Schools and workplaces provided structured settings for social interactions that allowed opportunities for individuals to meet peers and learn social skills. Surprisingly, it was the social aspects rather than the academic or task oriented aspects that dominated discussions surrounding school and work. For example:

Interviewer: Is there anything else you enjoy about school?

Participant: Kind teachers, kind friends...playing basketball at school (16 year old male).

Social Challenges at School/Work

Unfortunately, even when participants reported a great number of social supports in the schools and workplaces, some social challenges were also present. In the school environment some students mentioned difficulties fitting in with their peers while others discussed overt aggression that they had experienced from their peers. The social difficulties students experienced, at times, resulted in a sense of isolation and a lack of social relationships for the participant. One adolescent in our study described it in this way:

Interviewer: What about the other things at school – like lunch time....I'm not sure if you get recess but during your breaks, is there anything you find challenging then?

Participant: Trying to talk to people.

Interviewer: Ok, why do you find that challenging?

Participant: Because they're always with their other friends and they're ignoring other people when they're at lunch or at a five minute break (13 year old female).

In other instances, there were overt aggressive acts towards the participants. One example of this is an instance of emotional aggression displayed at a high school involved in our study.

Interviewer: Is there anything else you that gave you difficulties in school this year?

Participant: Some kids picking on me.

Interviewer: In your same grade?

Participant: Yeah.

Interviewer: That's too bad. And what did you do about that? Did you do anything?

Participant: I got really angry and fought back and got in trouble by the principal and I stopped doing that.

Interviewer: And how did the other kids react when you fought back?

Participant: All they did is just laugh (16 year old male).

In the workplace, the social challenges included difficulties being assertive as well as difficult behaviours that the individuals displayed in the work place. An example of the former was:

Anything difficulty? Yes, it's hard for me actually, I talked to my tutor and she's going to work with me on it. It's problems – I tell my mom and dad about it too, I have to talk things out with somebody and I'm kind of scared and I hate to hurt somebody's feelings and if a person doesn't do their job, I hate saying "you can clean this, this is a job for cleaning," kind of thing and if I have problems I go see my supervisor and she can be in the room at the same time. So I have to be by myself and some other lady and....so that's what I need to work on (40 year old female).

An example of a difficult behaviour that was at times present in the workplace was aggressiveness. On one occasion, one of the participants in this study became aggressive with a customer at the work environment and this resulted in damage to his social standing. Following the incident his co-workers were unsure of how to interact with this individual for fear of another aggressive episode. His employer would assign him tasks with caution and would take care not to overwhelm him.

Social Support from Religious Organizations

Outside of the school and work settings, church was identified as an important social setting for persons with disabilities. Many of the participants attended church regularly and valued their time there. In general, comments suggested that it was the social environment and the informal support of the “church family” that assisted individuals with disabilities in their community living. One young adult participant articulated this concept in this way:

Yes I go to church. It makes me feel part of my community.
People at church pray for me and care about and encourage me.
I feel I belong (18 year old male).

Furthermore, parents identified church as a support for themselves and stated that it helped them in their parenting. Knowing that there were people who cared and thought about their children seemed to help them face challenges. One mother stated how she relied on the social support in her church:

I rely on their prayers for my kids – for both my kids - and they have prayed [him] through some big transitions like now – adjusting to [college] because I know that’s a support for me – knowing there are people praying, asking how he’s doing and that sort of thing. But as far as physical supports, it’s spiritual support without a doubt, but physical support...not really (mother of 18 year old male).

The Rural Advantage

Related to the discussions of social supports, families living in rural communities talked about a “rural advantage” to inclusion. Parents stated that, in their rural communities, their children were not seen for their disabilities, rather, they were viewed as individuals. One family’s experience in a rural setting was described in this manner:

Father: And we do have a good network of kids—friends—that have totally accepted him for what he is. And haven’t tried to ostracize him at all for his disability at all. Everybody’s accepted him—

Interviewer: Right.

Father: —and all of that.

Mother: Yes, that’s just [him]. That’s it.

Father: It’s just the way he is.

Mother: Yes. That’s just him.

Father: And it is because we’re living in a smaller town. Whether he’s going to get the best education in the world is another story, but I think all this interaction, this social interaction, is [inaudible].

Mother: Well, I think in some ways he probably gets a better—lots of things he probably does get better (mother and father of 12 year old male).

Often smaller communities do not have the specialized programs and formal supports that are available in the urban centers so inclusion is a necessity. The rural communities will often rally around the person with a disability to provide support in any way possible. Moreover, the rural

communities tend to offer activities that are less expensive when compared to the urban centers. For example many rural communities hold community fairs, carnivals, and concerts with many free or low priced activities. In the smaller communities, there are also many of the same activities as in the urban areas (e.g., swimming and bowling) but these events usually cost less in the rural settings. One mother described this advantage in this way:

I would say he probably has more of an advantage than even being in the city. He has a cousin that's a year younger, and he gets to do almost nothing because everything costs more money, and the driving (mother of 17 year old male).

Finances are a challenge for many persons with disabilities because of limited funding provided by the provincial government to cover both living and recreational expenses. Many participants and parents in our study discussed the financial challenges that they face because the Assured Income for the Severely Handicapped (AISH) simply does not allow for many *extras* and usually just covers the essential living expenses. Therefore, less expensive activities are extremely important for an individual's social life.

Discussion

With the advent of the inclusion movement, the importance of friendship and social supports for persons with developmental disabilities has taken centre stage. During our interviews with the participants and their families many social aspects of inclusion surfaced. Social support comes from many settings in the community such as school, work, church, and the community as a whole. As stated in current inclusion literature (McDonald & Thomas, 2003; Stainback & Stainback, 1987), for community living to be satisfying, these supports are essential. Unfortunately, there are still social obstacles that many individuals with disabilities need to overcome. These obstacles are similar to those identified by Giangreco et al. (1993) in the inclusive classroom. It is of utmost importance that these challenges are examined and resolutions are sought out so all individuals can reap the benefits of being included

in these social environments. Furthermore, it seems that many urban centres can learn from their rural counterparts in regards to informal strategies to promote inclusion. Many rural communities demonstrate that there is not necessarily a need for special programs; rather, an attitude shift is more effective. This attitude shift comes with increased awareness within each community. As individuals with disabilities are more visible in the community, other community members begin to experience and understand the benefits of inclusion and the contributions persons with disabilities can make to the community. With increased visibility comes increased acceptance (Turnbull et al., 1999). Moreover, education is of utmost importance in this attitude shift. By educating our children about disabilities, they are more likely to hold accurate perceptions of persons with disabilities. In many cases, these new perceptions will be brought back to the homes where the parents will begin to learn more accurate information about disabilities as well.

Limitations

Given the nature of this research, there are a few considerations that need to be acknowledged. In qualitative research, participant checks are often completed to allow for the clarification of any ambiguous interview data. This is usually done by allowing the participants of one's research to review the interview transcripts and correct any misrepresentations. Due to the nature of the disabilities in this sample, however, review of the written transcripts was not possible. Most of the participants with disabilities in this research did not have the literary skills to complete such a review. Moreover, because of financial and time constraints, verbally reviewing the transcripts with each participant was not feasible. To assist in interpretation of the transcripts, however, a conversation immediately following each interview took place to discuss any confusion the researcher may have been feeling.

Another problem in this type of research is the abstract nature of the concepts *friendship* and *social relationship*. At times, the participants in this project struggled with their descriptions of the importance of relationships in their lives. For many persons with developmental disabilities, abstract concepts are difficult to fully understand, and some

individuals can struggle with their articulation of such concepts. Due to this challenge, the researchers were careful to explore the participants' definitions of such concepts so it was clear what each participant was referring too when he/she talked about *friends* and *relationships*. In addition, a follow up component to this project is currently underway in which arts based techniques are being used to assist in making the concepts more concrete. Participants are being asked to draw pictures of their social experiences. This approach allows them to discuss their stories in a concrete manner, as well as allowing them another medium through which to communicate.

Future Directions

The findings of this research clearly identified social supports as a critical factor in the lives of individuals with developmental disabilities and, therefore, it is of utmost importance that the research community continue to research strategies to promote friendships in inclusive settings. While there are many programs that are aimed at building these relationships, there is little empirical investigation into the success of such programs. The rural advantage, discussed in this paper, most prominently identified the importance of informal social supports for persons with disabilities. Further research needs to be completed on how to further build informal supports into the lives of persons with disabilities.

Additionally, future research needs to be completed to investigate the current definitions of inclusion. In the past, many educators and family members have identified inclusion as individuals with disabilities having interactions with non-disabled peers. Our research has, however, identified the important role that peers with disabilities can play in the inclusion of persons with developmental disabilities. A broader definition of inclusion is needed to include such characteristics, and it is important that we further investigate the perceptions of the key players, the persons with disabilities, to better understand what inclusion means to them.

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